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Bioethical and Medicolegal Implications of Withdrawing Artificial Nutrition and Hydration from Adults in Critical Care

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Abstract

The withdrawal of artificial nutrition and hydration or other life-sustaining treatments is a clinical decision, made in ICUs or in other settings, involving patients suffering from serious and irreversible diseases or impaired consciousness. Such clinical decisions must be made in the best interests of the patient, and must respect the wishes previously expressed by patients, laid down in their wills, in advance directives or in information passed on by relatives or legally appointed health-care agents, and in observance of common bioethical and legal rules in individual nations. Intensivists who are expert in the management of life-sustaining treatments are also involved in deciding when to withdraw futile therapies and instigate end-of-life care procedures for dying patients, with the sole aim of providing comfort and ensuring that suffering is not prolonged unnecessarily.

List of Abbreviations

ICU Intensive care unit

Introduction

End-of-life care procedures, including the withdrawal of artificial nutrition and hydration, demand from staff the same level of technical competence required in providing life-sustaining treatments but may appear to be more controversial because of the very nature of the intensive care setting and the specific skills possessed by and the demands made of the physicians working in ICUs (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

The main aim of intensive care medicine is to treat acute life-threatening diseases in order to assure a positive outcome, with the patient's survival and eventual discharge.

While physicians and nurses working in ICUs have extensive knowledge, experience, and technical skills which are mainly directed toward providing life-sustaining treatments, ensuring survival, and restoring the quality of patients' lives, they may sometimes not consider terminal care procedures to be as relevant as other activities performed in the intensive care setting (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

The admission of a patient to an ICU represents, above all, a therapeutic challenge to the clinical team, but when all treatments fail, the physicians and the nursing staff, as well as patients and their families, have to consider the transition from curative to palliative care (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

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It may, for a variety of reasons, sometimes be difficult to make a decision involving the withdrawal of life-sustaining support from a terminally ill patient admitted to an ICU due to an impaired neurological state, sedative or opioid therapy, or tracheal intubation, because:

(a) The patient, if an adult, has not left an advance directive.
(b) There is a lack of information regarding his or her values and wishes.
(c) There are no parents, relatives, or health-care agents.

Physicians are clearly not obliged to continue unsuccessful or futile treatments and are certainly concerned that ethical and legal principles should be upheld while also acting in the patient's best interests (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

On the other hand, the switch from providing life-sustaining treatment for a patient to preparing for his or her death, which normally means providing comfort and palliative treatments, whether in an ICU or in other clinical settings, requires intensivists to recognize that:

(a) Withdrawing life support in cases of serious and irreversible diseases or impaired consciousness may be considered to be in the best interests and wishes of the patients while also preventing futile treatments and prolonged suffering.
(b) Withholding and withdrawing life support, if respectful of bioethical and legal rules, are equivalent medical approaches.
(c) Withdrawing life support means that the patient is *allowed* to die, which is most definitely not the same as euthanasia.
(d) Administering drugs in order to make the patient comfortable (even though this will, in all probability, hasten the patient's death) does not imply an intention to cause the patient's death.
(e) The withdrawal of life support may be a common occurrence, but the denial of special care, such as comfort-giving and palliative treatments, should under no circumstances occur.
(f) Withdrawing life support has to be regarded as one of many critical care procedures to be used during the dying phase and included in the experience and technical training of physicians and other professionals working in ICUs (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000) (Table 1).

Once the transition from treatment to comfort and palliative care has been made, those interventions which do not contribute to the patient's comfort will be suspended. These may include the

Table 1 Principles of withdrawing life support in adult patients in ICUs

Withdrawing life support in cases of serious and irreversible diseases or impaired consciousness is planned in the best interests and wishes of the patients and to prevent futile treatments and prolonged suffering
Withholding and withdrawing life support are equivalent medical approaches when applied in the respect of bioethical and legal rules
Withdrawing life support means that the patient is *allowed* to die; this is not conceptually the same as euthanasia
While hastening the patient's death, the prescription of drugs in order to make the patient comfortable does not imply the intention to cause the patient's death
The denial of special care, such as comfort-giving and palliative treatments, should under no circumstances occur when withdrawing life support is started
Withdrawing life support should be regarded as one of many critical care procedures to be used during the dying phase and included in the experience and technical training of physicians and other professionals working in ICUs

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cessation of artificial nutrition and hydration and the suspension of the use of vasoactive drugs, antibiotics, blood products, or other treatments. It may also involve the withdrawal of invasive cardiorespiratory monitoring, mechanical ventilation, noninvasive mechanical ventilation, mechanical cardiocirculatory support, renal dialysis, etc. and the writing of a do-not-resuscitate order. Drugs such as opioids and benzodiazepines or other sedatives which control the discomfort caused by pain, dyspnea, and respiratory stress will be prescribed and titrated as for any other pharmacological intervention in critical care practice (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

Medical records will include all data concerning terminal clinical conditions and document the clinical steps and decisions arising from meetings with the adult patient and surrogates leading up to the decision to withdraw life support. These notes will also document plans for withdrawal therapies and resuscitation, the drugs used for sedation and analgesia, and the do-not resuscitate orders (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

Lastly, the responsibility of physicians and nurses toward the patient does not end when the decision to withdraw life-sustaining treatment is taken but continues right through the dying process. This demands the same level of care and skill shown when patients are admitted to ICUs and must therefore be considered as a normal medical procedure and of no less importance (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

The management of the dying process of a critically ill patient has nowadays to be regarded as a key professional skill for physicians involved in end-of-life care (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

Applications to Intensive Care: Bioethical and Medicolegal Implications

The withdrawal of artificial nutrition and fluid support as well as other life-sustaining therapies is sometimes practiced in Europe and North America with patients suffering from benign or malignant diseases, where the prognosis is severe and irreversible, or in cases of impaired consciousness (coma, permanent vegetative state, brain death). This process may involve patients admitted to medical or surgical wards or to ICU departments.

Decisions to withdraw artificial sustenance and other life-sustaining supports bring physicians and intensivists face to face with their ethical responsibilities, the specific laws of individual countries, and the potential conflict between them. In those cases where no advance directives exist, where it is impossible to know the wishes of the incompetent patient and where the physicians and family fail to reach agreement, the courts will be asked to intervene.

Legal codes generally acknowledge that physicians do not have to provide treatment which they consider to be futile or against the patient's interests, while recognizing the rights of each patient to receive care based on certain standards of competence and behavior, below which a physician may be guilty of negligence or perhaps even criminally responsible (Korner et al. 2006).

All doctors should know if and when treatment is futile or excessively aggressive and should promote the concepts of palliative support, symptom relief, and preservation of dignity (Korner et al. 2006).

The basic ethical duties in medical practice are beneficence (the duty to promote good and act in the best interests of the patient and his health), nonmaleficence (the duty not to harm the patient), respect for the patient's autonomy, dignity and choices, together with the concepts of truth-telling and informed consent (Snyder 2012).

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Table 2 Competent adult patients preparing a written statement on end-of-life preferences or choosing a surrogate must be able to

Understand what the proposed treatments consist of, why they are being proposed, and why the alternatives are being rejected
Understand the potential benefits, risks and complications, possibility of failure, existence of alternative treatments, and futility of certain treatments
Understand the consequences of refusing the proposed treatments, retain the information given, reflect and make a pondered decision, or indeed change any decision at a later stage
Make decisions freely and without any kind of psychological pressure

Table 3 In cases of patients who are no longer competent, family and physicians should take into account

All prior oral or written statements concerning the maintenance, rejection, or interruption of life-sustaining treatments
The ascertainment of the adult patient's presumed wishes on the basis of information gleaned from parents, relatives, friends, or witnesses in cases where there is no written statement
That a final decision on withdrawing artificial nutrition and hydration will have to be delivered by a court

Although the laws in different countries and the ways in which they are applied are evolving to keep pace with the development of new medical-ethical values, physicians must always remember that, as law-abiding citizens and members of a profession, they are bound to respect and apply the laws of their country when taking a decision to withdraw life-sustaining treatment (Snyder 2012).

These interactions between medical ethics and the law are even more problematic in those cases where adult patients have lost their decision-making capacity. As a result, in many countries laws exist which allow people, while still in possession of their faculties, to prepare a written statement of their end-of-life preferences and choose a surrogate to act on their behalf should they be unable to express their own health-care decisions.

Competent adult patients should be told by physicians about the severity of their clinical conditions and their prognosis and must be able to:

(a) Understand what the proposed treatments consist of and why they are being proposed or why alternatives are being rejected.
(b) Understand the potential benefits, risks and complications, the possibility of failure, the existence of alternative treatments, and the futility of certain treatments.
(c) Understand the consequences of refusing the proposed treatments and be able to retain the information given to them so that they can reflect and make a pondered decision or indeed change their decision at a later stage.
(d) Make decisions freely without being subjected to any kind of psychological pressure (Korner et al. 2006; Snyder 2012) (Table 2).

When an adult patient is prey to a serious, incurable, and terminal condition and is no longer competent, all his or her prior oral or written statements concerning the maintenance, rejection, or interruption of life-sustaining treatment will be taken into account by physicians (Korner et al. 2006; Snyder 2012) (Table 3).

This principle is implicit in article 9 of the Convention on Human Rights and Biomedicine, approved by the European Council in Oviedo in 1997. It states that "The previously expressed

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Table 4 Essentially the official, legally recognized document known as an advance directive include

Any written preferences concerning the end-of-life treatment should the patient no longer be able to make decisions due to illness or incapacity
The *living will*, which is the list of all medical procedures and life-sustaining measures the person agrees to or rejects, including mechanical ventilation, renal dialysis, artificial nutrition, and hydration via feeding tubes or intravenous catheters, and the wish to donate organs or not
The *medical or personal welfare power of attorney*, which nominates a health-care agent who is authorized to take medical decisions should the signatory become incompetent
The *do not resuscitate order* which prohibits cardiopulmonary resuscitation should the patient experience cardiorespiratory arrest

wishes relating to a medical intervention by an adult patient who is not, at the time of intervention, in a state to express his or her wishes, shall be taken into account."

Specific preferences for care involve the refusal or acceptance of any medical, surgical, or resuscitative treatment, including the use of artificial sustenance and life-sustaining procedures, and the right to be given all relevant information about the diagnosis and prognosis of the illness (Korner et al. 2006; Snyder 2012).

All the specific wishes of an adult patient should be included in an official, legally recognized document, known as an advance directive, which contains written preferences concerning their end-of-life treatment in the event that he or she is no longer able to make decisions due to illness or incapacity (Korner et al. 2006; Snyder 2012).

Family, physicians, and the courts will evaluate this information if adult patients are unable to make their own health-care decisions or to express themselves because they are in a coma or a vegetative state or are afflicted by other irreversible diseases or unexpected end-of-life situations (Korner et al. 2006; Snyder 2012).

Advance directives generally include the following:

(a) A *living will*, which is a list of all medical procedures and life-sustaining measures the person agrees to or rejects, including mechanical ventilation, renal dialysis, artificial nutrition, and hydration via feeding tubes or intravenous catheters, and whether they wish to donate their organs or not.
(b) A *medical or personal welfare power of attorney*, which nominates a health-care agent who is authorized to take medical decisions should the signatory become incompetent. The health-care agent so designated will act on the adult patient's behalf and interpret his or her wishes even in situations not directly covered in the text of the living will. The designated agent may also act on behalf of the incapacitated person when his or her family opposes the patient's wishes as described in the living will.
(c) A *do-not-resuscitate order* which prohibits cardiopulmonary resuscitation should the patient experience cardiorespiratory arrest (Table 4).

When physicians consider that a patient's advance directives are not acceptable or applicable, it will become necessary to refer to hospital protocols or its ethics committee or to the laws of the country in question (Korner et al. 2006; Snyder 2012).

A person suffering from an irreversible or terminal illness frequently has no decision-making capability, has not drawn up an advance directive, or did not nominate a health-care agent (Korner et al. 2006; Snyder 2012).

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In this case every decision regarding the choice of withholding or withdrawing treatment must be taken in the patient's best interests, and respect their presumed wishes on the basis of information gleaned from parents, relatives, friends, or witnesses. Obviously, in the absence of any clear instructions, staff should attempt to understand what the adult patient would have chosen by learning about his or her moral values and opinions concerning end-of-life care (Korner et al. 2006; Snyder 2012).

These discussions should be held with the family, the hospital staff and ethics committee, and, if necessary, the courts (Korner et al. 2006; Snyder 2012).

In cases where an incompetent adult patient has no family, friends, or agent, it may be necessary to resort to the courts for a decision on withholding or withdrawing medical support and artificial sustenance (Korner et al. 2006; Snyder 2012).

The withholding and withdrawal of life-sustaining treatments should be regarded as of equal medical and technical validity, with both being in accordance with the patient's dignity and freedom to decide, so long as they are carried out in conformity with a country's ethical codes and legislation, with the patient's advance directives (be they documented or surmised) and in his/her best interests (American Medical Association 2006; British Medical Association 1999; American Academy of Neurology 1989; Snyder 2012).

Where treatment, including artificial nutrition and hydration, proves to be of no benefit to the patient, is excessively painful or detrimental, or results in unbearable psychological suffering, it can be halted if so requested by a competent adult patient or surrogate or as a consequence of a decision taken by the medical team when there is clearly no moral or legal obligation to provide or continue a treatment that is not in the patient's best interests (Jennett 2002; American Medical Association 2006; British Medical Association 1999; American Academy of Neurology 1989; Snyder 2012).

This means that in many countries, doctors may not legally end life but are not ethically and legally required to prolong the process of dying. The idea of prolonging life is a worthy medical objective, but therapeutic obstinacy may harm patients and rob them of their dignity (Korner et al. 2006).

Nowadays, in many European countries and in the North America, both in common and civil law systems, the principle of self-determination is considered a fundamental constitutional right, which allows every informed citizen to accept or refuse medical treatment.

Legal systems and the courts generally approach every decision involving the withholding or withdrawal of artificial nutrition and hydration or other life-sustaining procedures by observing the following steps in adult patients:

(a) The patient's advance care plans must be written when he or she still retains full decision-making capacity.
(b) The patient's real desires must be ascertained, in the form of a written profile of his or her personality and moral principles, prepared by the health-care agent, parents, relatives, friends, or witnesses.
(c) The utility or futility of medical treatments and life-sustaining interventions must be evaluated with the patient's best interests in mind.
(d) Diagnosis of the disease, the severity of the patient's clinical conditions, and the chances of reversibility of the illness must be established.
(e) The patient's prognosis must be determined.
(f) The treatments which might be suspended must clearly be recognized as genuine medical treatments (at the present time artificial nutrition and hydration are internationally regarded as medical treatments and can therefore be refused by the patient).

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(g) The patient's advance refusal of specific medical treatments, such as artificial nutrition and hydration, must be proven.
(h) Exactly what the physicians will and will not do, once official authorization to proceed has been given, must be documented (American Medical Association 2006; British Medical Association 1999; American Academy of Neurology 1989; Snyder 2012) (Table 5).

The withdrawal of artificial nutrition and hydration or other life-sustaining support in a pediatric context is more controversial than with adults because children or neonates are not able autonomously to make advance decisions concerning the acceptance or rejection of medical treatments. Moreover, the withdrawal of artificial nutrition and hydration usually has a significant emotional impact on parents and health-care professionals because our knowledge of the level of perceived discomfort in the infant is incomplete. It is also true that nutrition and hydration, especially in children and babies, are regarded as a fundamental right and physiological need rather than as medical treatment (Ellershaw et al. 1995; Winter 2000; Diekema and Botkin 2009; Tsai 2011).

Although these controversies cannot always be resolved, the withdrawal of artificial nutrition and hydration in terminally ill children, as in adults, is ethically and clinically acceptable in certain circumstances.

Diekema and Botkin consider that the withdrawal of nutritional and fluid support can be clinically permissible when there is consensus that it is not producing a net benefit for the child (Diekema and Botkin 2009).

Specifically the following principles must be respected:

(a) Children capable of eating and drinking and showing signs of wanting to eat or drink must be given food and fluid support.
(b) The products used for artificial nutrition and hydration amount to medical interventions which may be withheld or withdrawn just like other medical treatments.
(c) Decisions to withhold artificial nutrition and hydration should be of overall benefit to the child, and such treatments may be withdrawn when they serve merely to prolong the dying process while producing limited or no net benefit. The decision to withhold or withdraw artificial nutrition and hydration should always be made in the child's best interests.
(d) The child deprived of artificial nutrition and hydration should be kept as comfortable as possible with comprehensive palliative care, including appropriate analgesia, sedation, oral hygiene, and humidification (Diekema and Botkin 2009; Tsai 2011).

Table 5 Legal systems and the courts approach decisions involving the withholding or withdrawal of artificial nutrition and hydration or other life-sustaining procedures by observing

The patient's advance care plans written while still possessing full decision-making capacity
The patient's real desires, in the form of a written profile of his or her personality and moral principles, prepared by the health-care agent, parents, relatives, friends, or witnesses
The utility or futility of medical treatments and life-sustaining interventions evaluated with the patient's best interests in mind
The diagnosis of the disease, the severity of the patient's clinical conditions, and the chances of reversibility of the illness
The patient's prognosis
The treatments which might be suspended (at the present time artificial nutrition and hydration are internationally regarded as medical treatments and can therefore be refused by the adult patient)
The patient's advance refusal of specific medical treatments, such as artificial nutrition and hydration
What the physicians will and will not do, once official authorization to proceed has been given

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Despite public and scientific disputes past and present, artificial nutrition and hydration are now generally considered to be medical interventions and therefore subject to the same principles of patient acceptance or refusal as other medical treatments (e.g., drug therapies, mechanical ventilation, cardiocirculatory support, dialysis, etc.) (American Medical Association 2006; British Medical Association 1999; American Academy of Neurology 1989; Snyder 2012).

There are several clinical and technical reasons for claiming that artificial nutrition and hydration constitutes a medical treatment. Firstly, the administration of fluids and nutrition necessitates the use of medical equipment and is not a simple nursing procedure. Secondly, the procedure also demands accurate medical diagnostic and prognostic judgments and an objective evaluation of the advantages and disadvantages of its application. Thirdly, the patient undergoing artificial nutrition and hydration requires careful and continuous surveillance in order to prevent a range of dysmetabolic, infective, or technical complications (problems involving catheters, pumps, the positioning of tubes, or the insertion of catheters are all clinically well documented). Fourthly, the manufacture of products for artificial nutrition and hydration is the result of complex, standardized pharmaceutical procedures. Lastly, as with any medical treatments, artificial nutrition and hydration may fail to provide any real benefit to the patient or offer any hope of recovery, which means that there can be no ethical or medical obligation to continue providing it. In short, artificial nutrition and hydration which do not provide benefit to the patient and only prolong the dying process, without offering any hope of cure, can be stopped when it is clear that the patient would not want to receive any further medical treatment and when the family is in agreement (American Medical Association 2006; British Medical Association 1999; American Academy of Neurology 1989; Snyder 2012).

Given the continuous evolution of ethical principles and the promulgation of new legal directives involving end-of-life plans, which are currently being debated in many parts of the world, the level of perceived discomfort and the specific final causes of death following the withdrawal of artificial nutrition and hydration continue to generate considerable pathophysiological, clinical, and medico-legal interest (Buiting et al. 2007; Bonito et al. 2002; Perry et al. 2005; Breitbart 2005; Solarino et al. 2011; Moratti 2010; Pasman et al. 2005; McCann et al. 1994; Moreschi et al. 2013).

The cessation of artificial sustenance and life-sustaining care in cases of permanent vegetative state continues to be hotly debated. The debate focuses chiefly on the possibility that the patient might recover and on the patient's hypothetical ability to perceive and process externally some signals from the surrounding environment (American Academy of Neurology 1989; Bonito et al. 2002; Jennett 2002; Wade and Johnston 1999).

The withdrawal of artificial nutrition and hydration and life-sustaining support from patients in permanent vegetative states may be controversial for some physicians who claim that (1) there exists a chance, albeit remote, that there might be improvement in patients in states of impaired consciousness and (2) the patient may be capable of minimal conscious processing of signals perceived from the external environment. In any case, there is no clinical or instrumental data which enable us to predict the likelihood of neurological improvement in a patient in a state of impaired consciousness. At present no advanced neurophysiological investigations have been conducted which could help us to predict a favorable outcome or which demonstrate a minimal ability to process external signals when in a permanent vegetative state (Rosanova et al. 2012; Lehembre et al. 2012; Katz et al. 2009).

Two emblematic cases were those involving Terri Schiavo in the USA in March 2005 and Eluana Englaro in Italy in February 2009.

Terri Schiavo had experienced acute cardiac failure and ventricular fibrillation in 1990 due to an extremely low blood potassium level caused by an eating disorder and dieting. The cardiorespiratory failure caused a global anoxic-ischemic encephalopathy, typically characterized by diffuse brain edema and diffuse laminar cortical necrosis, resulting in multifocal cerebral atrophy, diffuse

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ventriculomegaly, and a permanent vegetative state. Fourteen days after the courts had authorized the withdrawal of artificial nutrition and hydration, she died of marked dehydration as a direct result of the electrolyte, and hypovolemic disturbances brought about the lack of hydration (Bonito et al. 2002; Perry et al. 2005; Breitbart 2005).

Eluana Englaro suffered neurological lesions as the result of a motor vehicle accident which caused severe brain trauma (diffuse brain edema and bilateral hemorrhagic contusions in the frontal and temporal regions, basal ganglia, thalamus, mesencephalon, cerebellum, medulla oblongata) and upper cervical cord trauma (edema and hemorrhagic contusions in the anterior, lateral, and posterior columns) which resulted in diffuse multifocal brain and upper spinal cord atrophy with hemosiderinic pigmentation and a consequent permanent vegetative state and quadriplegia. The courts authorized the withdrawal of artificial nutrition and hydration, and 87 h later she died of cardiorespiratory and renal failure compatible with serious dehydration. This induced lethal hyperthermia and cardiovascular collapse in a quadriplegic patient who had chronic impairment of thermal and hemodynamic modulation due to the autonomic denervation resulting from the previous spinal cord trauma (Solarino et al. 2011; Moratti 2010; Moreschi et al. 2013).

Forensic pathologists who examined the corpses and the clinical records in the two different cases of Terri Schiavo and Eluana Englaro were asked by the courts to ascertain the following:

- Establish the cause of death.
- Ensure that lethal drugs had not been administered after the court's decision.
- Verify the correct application of supportive care during the end-of-life phase.
- Ascertain perceived discomfort during the withdrawal of artificial nutrition and hydration and the terminal pathophysiological steps in the period immediately prior to death (Bonito et al. 2002; Perry et al. 2005; Breitbart 2005; Moreschi et al. 2013).

In both the Terri Schiavo and Eluana Englaro cases, the coroners found no significant signs of perceived discomfort due to starvation, which is in accordance with the data published by other authors who studied discomfort levels during the end-of-life phase in patients whose artificial nutrition and hydration have been withdrawn (Bonito et al. 2002; Perry et al. 2005; Breitbart 2005; Moreschi et al. 2013).

There is no published scientific evidence which confirms that the withdrawal of artificial nutrition and hydration induces discomfort or extra suffering in patients in the final phase of their lives (McCann et al. 1994; Moreschi et al. 2013).

Pasman et al. reported that terminally ill patients who are barely or no longer eating or drinking and those from whom artificial nutrition and hydration had been withdrawn display no significant differences in the perception of discomfort (Pasman et al. 2005; Moreschi et al. 2013).

McCann et al. reported that feelings of hunger, thirst, dyspnea, agitation, anxiety, and pain in terminal oncological patients were only slightly lessened during the administration of food and fluids requested by the patient (McCann et al. 1994; Moreschi et al. 2013).

Furthermore the administration of drugs such as opioids or sedatives, prescribed to alleviate pain, as well as the humidification of mouth mucosal districts, proved to be clinically sufficient to control discomfort in patients who are experiencing the initial signs of hunger and thirst (Pasman et al. 2005; McCann et al. 1994; Moreschi et al. 2013).

After the cessation of artificial nutrition and hydration and before death due to cardiovascular decompensation, patients perceive little or no discomfort. Systemic decompensation occurs slowly because it is associated with the activation of specific biochemical pathways and occurs very slowly (Pasman et al. 2005; McCann et al. 1994; Moreschi et al. 2013).

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Kerndt et al. reported that the first 24 h after the onset of fasting are normally sustained by glycogenolysis, while during the following eight or more days, gluconeogenesis, protein catabolism, and the oxidation of fatty acids and ketosis ensure the patient's survival. The support provided by these biochemical pathways alleviates the perception of discomfort and delays the inevitable onset of death by several days (Kerndt et al. 1982; Karlawish et al. 1999; Faber-Langendoen and Lanken 2000; Qaseem et al. 2008; Barr et al. 2013; Moreschi et al. 2013).

Various authors report that in fasting subjects, the burning of fat is the last biochemical pathway in operation before death and is capable of sustaining the peripheral tissues and central nervous system (Pasman et al. 2005; McCann et al. 1994; Moreschi et al. 2013).

The onset of death is consequently gradual, taking several days from the initial appearance of anuria, and this is due to the production of energy and endogenous water which are available from fat combustion through the oxidation of fatty acids and ketosis and are able to sustain the body's demand for energy and water and mitigate any perception of discomfort (Pasman et al. 2005; McCann et al. 1994; Moreschi et al. 2013).

In the cases of both Terri Schiavo and Eluana Englaro, death was due to terminal cardiovascular collapse, induced by dehydration. The coroners established that this happened slowly in the demise of Terry Schiavo (terminal dehydration with electrolyte disturbances brought about by the lack of hydration) and rapidly in the case of Eluana Englaro (terminal cardiovascular and renal failure with hyperthermia brought on by the lack of hydration in a quadriplegic subject with basic thermal and hemodynamic dysregulation).

The real cause of death following the withdrawal of artificial nutrition and hydration is not the fasting and starvation per se but two specific disturbances which have serious pathophysiological effects on hemodynamic status and thermal regulation:

1. Dehydration and the consequent volemic depletion cause various cardiovascular effects.

   Hemodynamic perturbation occurs with the reduction in left ventricular filling and stroke volume associated with a compensatory tachycardia with a consequently reduced ability to perfuse peripheral tissues (Dill and Costill 1974; Nadel 1981; Strydom and Holdsworth 1983).

   The human body cannot compensate for acute and persistent volemic depletion due to dehydration and may suffer from dangerous progressive hemodynamic decompensation.

   In the absence of adequate hydration, the subject is unable to compensate for the hypovolemic condition induced by dehydration, and this leads to progressive fatal cardiovascular decompensation (Dill and Costill 1974; Nadel 1981; Strydom and Holdsworth 1983).
2. Body temperature is normally regulated by the balance between heat production and heat dissipation. An increase in body temperature occurs when heat production exceeds heat dissipation, when dissipation is impaired, or when there is excessive ambient heat.

   Heat produced by the metabolism, or superficially absorbed when ambient temperatures exceed body temperature, is mainly dissipated at the skin's surface. Thermal dissipation via the skin occurs through convection during peripheral skin vasodilatation and evaporation during sweating (Strydom and Holdsworth 1983; Harvey 1993; Shapiro and Seidman 1990; Simon 1976).

In response to an increasing core body temperature, the thermic center, situated in the preoptic nucleus of the anterior hypothalamus, induces the efferent fibers of the autonomic nervous system to promote peripheral blood redistribution with skin vasodilatation and sweating.

Volemic depletion, as occurring during dehydration, is a crucial factor in that it impairs heat dissipation through decreased blood pressure and cardiac output and limited peripheral perfusion

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and sweating, so that intravenous fluids and cooling of the body's surface are required if the lethal consequences of hyperthermia are to be avoided (Dill and Costill 1974; Nadel 1981; Strydom and Holdsworth 1983; Harvey 1993; Shapiro and Seidman 1990; Simon 1976).

In a state of prolonged, severe dehydration, adult body temperature can increase to above 38–40 °C for hours or days. Without fluid therapy and cooling, dangerous complications may occur, including hypotension, tachycardia, arrhythmia, hyperventilation, rhabdomyolysis, disseminated intravascular coagulation, renal tubular necrosis, abnormal liver function, and congestive heart failure. Typical laboratory findings are hemoconcentration, proteinuria, ematuria, hypoxia, early respiratory alkalosis, late lactic acidosis, hypoglycemia, hypokalemia, hypophosphatemia, hypomagnesemia, and hypocalcemia. The resulting terminal events are shock, myocardial ischemia, renal failure, serious neurological impairment, and cardiac arrest (Harvey 1993; Shapiro and Seidman 1990; Simon 1976).

Dehydration therefore causes an abnormal rise in core temperature and low cardiac output with reduced oxygen delivery to tissues. This in turn leads to progressive decompensation with cardiovascular failure, renal failure, lactic acidosis, myocardial ischemia, and central neurological impairment. In these conditions, death often occurs swiftly (Harvey 1993; Shapiro and Seidman 1990; Simon 1976).

Terminal cardiorespiratory arrest occurs due to severe arrhythmia (atrial flutter, ventricular tachycardia, ventricular fibrillation) caused by lactic acidosis and dehydration-related electrolyte depletion (loss of potassium, magnesium, and calcium). Frequent and significant postmortem observations include:

(a) Dry appearance of cutaneous, subcutaneous, and mucosal areas; significantly sunken eyes and dry eyelids; and dry serosal membranes at the peritoneal cavity, pleural cavities, and pericardial sac.
(b) Atrophy of cardiac muscle reflecting a decrease in heart mass; diffuse myocardial areas showing fiber blurring and contraction bands, with micro-necrotic and hemorrhagic lesions.
(c) Macroscopic and histological signs of acute pulmonary edema (diffuse foamy, rose-colored alveolar fluid, engorged capillaries, thickened alveolar walls, pink intra-alveolar transudates)
(d) Reduction in volume and consistency of both kidneys with histological signs of tubular necrosis and diffuse vascular congestion.
(e) Atrophy of the medullary regions of the suprarenal glands (Kerndt et al. 1982; Moreschi et al. 2013).

In order to reconcile the patient's well-being with his or her advance directives and input from family members, the decision to withdraw artificial nutrition and hydration or other treatments must be, in full observance of ethical and legal rules, the final step of a consensus-based decision-making strategy guided by physicians and involving family, health-care agents, and the clinical team in a progressive and structured manner (Kerndt et al. 1982; Moreschi et al. 2013).

The aim should be to reach consensus on diagnosis and prognosis (on the basis of existing data and clinical experience) and to understand the benefits and drawbacks of the various treatments available while acting within the law and responding to the patient's wishes and instructions. Surrogates should also be assured that everything possible will be done to relieve suffering and maximize dignity and quality of life during the terminal phase (Faber-Langendoen and Lanken 2000).

When the decision is taken to suspend artificial nutrition and hydration or other treatments which are proving to be of no benefit to the patient, the priority of the medical and nursing team will be to

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adopt an approach that recognizes the inevitability of death and focuses on the comfort of patients and their families. All the medical team's efforts must be oriented to meeting the physical, emotional, and spiritual needs of dying patients and their families. The ultimate challenge for clinicians assisting a terminally ill patient is to guarantee dignity and comfort and to ensure quality of dying and the prevention of any kind of discomfort, by administrating appropriate and adequate palliative pain control and/or sedation (Faber-Langendoen and Lanken 2000).

Guidelines and Protocols

Notwithstanding the very extensive literature on the ethical and medicolegal reasoning behind *whether* to withdraw life-sustaining supports, too little has been done in terms of research, quality improvement studies, and the training of ICU staff on *how* to withdraw such supports (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

This lack of standard protocols involving the practical aspects of withdrawing treatment (medication, artificial nutrition and hydration, mechanical ventilation and cardiocirculatory support, and dialysis) may sometimes give rise to the unsatisfactory management of end-of-life care for critically ill patients (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

This may sometimes result in an overly cautious and gradual approach to the withdrawal of life support or a poor choice of drugs and/or their titration.

Such a slow and gradual approach is not ethically or legally necessary and may expose the patients to excessive pain and discomfort, without providing any real benefit (Faber-Langendoen and Lanken 2000).

On the other hand, when the aim of intensive care treatment shifts to ensuring the patient's comfort during the dying process, a progressive and purposeful withdrawal of life-sustaining supports allied to the right dosage of palliative drugs may be justified, even if it hastens death (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

The development of quality improvement processes involving end-of-care procedures in ICU settings might promote the implementation of improved and updated protocols, the identification of better decision-making routes, and a withdrawal of life-sustaining supports which offers the greatest possible comfort to the patient (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000).

ICUs and clinicians should adopt protocols which enable them to:

(a) Evaluate the severity of clinical conditions (using severity of illness scores) and the prognosis and discuss objectives and treatment options.
(b) Ensure that in the implementation of any kind of triage, through the assessment of available resources in the ICU, strictly objective criteria are used to assign priority to one patient over another, while fully recognizing that triage does not condone abandonment of the patient.
(c) Verify the existence of a current advance directive or attempt to reconstruct the patient's principles and intentions.
(d) Avoid therapeutic obstinacy if there is no advance directive or if there are no family members or appointed agents.
(e) Interact appropriately with the patient, agent, family, and friends from a humane and professional point of view.

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(f) Obtain informed consent without forcing or rushing the patient, family, or agent into decisions.
(g) Identify and stop any treatment which is no longer effective, which is not desired by the patient, and which does not provide comfort.
(h) Form a plan for carrying out the withdrawal procedure (clearly identifying which treatments must be continued, withdrawn, or withheld and preparing do-not-resuscitate orders) and for handling complications.
(i) Move the patient to an appropriate setting and remove any electronic monitoring equipment, together with catheters, tubes, lines, and drains or any other devices which are no longer necessary and do not contribute to the patient's comfort.
(j) Use observational scores to evaluate the patient's pain and discomfort (a patient under tracheal intubation or with cognitive impairment due to pharmacological sedation, delirium, or dementia cannot report his or her symptoms) in order to minimize or eliminate the iatrogenic causes of physical or psychological pain.
(k) Prescribe the correct dosage and titration of opioids, sedatives, or other drugs to ensure the control of pain, dyspnea, respiratory distress, delirium, and agitated delirium.
(l) Ensure that the patient, family, and friends receive appropriate psychological, emotional, and pastoral support.
(m) Document all ethical, legal, clinical, and technical steps in the medical records.
(n) Evaluate the outcome of the withdrawal procedures adopted in order to improve end-of-care ICU procedures in the future.
(o) Extend psychological and organizational support to clinicians and ICU staff (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000; Barr et al. 2013; Moreschi et al. 2013) (Table 6).

Furthermore, if we accept that the withdrawal of life-sustaining treatments in ICU settings is in fact a medical procedure, we need to design and divulgate standard procedures and protocols aimed

Table 6 The progressive steps in the withdrawal of life support

Evaluate the severity of clinical conditions (using severity of illness scores) and the prognosis and discuss objectives and treatment options
Ensure that any kind of triage in the ICU, assigning priority to one patient over another, does not result in abandonment of the patient
Verify the existence of a current advance directive or attempt to reconstruct the patient's principles and intentions
Avoid therapeutic obstinacy if there is no advance directive or if there are no family members or appointed agents
Interact appropriately with the patient, agent, family, and friends from a humane and professional point of view
Obtain informed consent without forcing or rushing the patient, family, or agent into decisions
Identify and stop any treatment which is no longer effective, which is not desired by the patient, and which does not provide comfort
Form a plan for carrying out the withdrawal procedure, identifying which treatments must be continued, withdrawn, or withheld, and preparing do-not resuscitate orders and instructions for handling complications
Move the patient to an appropriate setting, and remove any electronic monitoring equipment, together with catheters, tubes, lines, and drains or any other devices which are no longer necessary and do not contribute to the patient's comfort
Use observational scores to evaluate the patient's pain and discomfort in order to minimize or eliminate the iatrogenic causes of physical or psychological pain
Prescribe the correct dosage and titration of opioids, sedatives, or other drugs to ensure the control of pain, dyspnea, respiratory distress, delirium, and agitated delirium
Ensure that the patient, family, and friends receive appropriate psychological, emotional, and pastoral support
Document all ethical, legal, clinical, and technical steps in the medical records

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at improving the end-of-life care of dying patients (Rubenfeld 2004; Siegel 2009; Truog et al. 2008; Puntillo et al. 2014; Faber-Langendoen and Lanken 2000; Barr et al. 2013; Moreschi et al. 2013).

Summary Points

- The withdrawal of artificial nutrition and hydration together with other life-sustaining supports in ICUs or other settings is a clinical response to cases of terminal adult patients suffering from irreversible diseases or who are in a state of impaired consciousness with no hope of improvement or recovery.
- Such clinical procedures should be pursued in the best interests of the dying patient and with the aim of avoiding therapeutic obstinacy, limiting suffering, and safeguarding the patient's dignity.
- The decision to withdraw artificial nutrition and hydration or other life-sustaining supports, in compliance with the ethical codes and legal systems in individual countries, should be the final step in a structured, professional, interactive process involving physicians, health-care teams, patients, and families or appointed agents.
- The management of the death process, including the withdrawal of artificial sustenance or life-sustaining treatments, is a medical procedure and does not equate to euthanasia; it demands specific professional skills from intensivists and ICU staff who are required to operate using standard procedures and protocols in order to improve the end-of-life care of dying patients.

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